Evaluation of a Patient Held Record in Cancer Care in Northern Ireland

Evaluation of a Patient Held Record in Cancer Care in Northern Ireland

Authors: Dr Kate Sullivan
Anne Devlin

Acknowledgment

In a career in the Health Service spanning over 30 years, one meets many people. Some of those individuals leave an indelible impression and influence on one's attitude and behaviour for ever. As chairperson of the Regional Patient Held Record Group, I felt very privileged to meet one such individual – Margaret.

Margaret agreed to meet with the group to share with us her personal journey from discovery of symptoms to diagnosis and treatment of Breast Cancer. Each member of the group felt humbled and yet inspired by the quiet dignity and the absolute honesty and openness of Margaret as she shared her experiences. Her story taught us many things not least that there was still room for significant improvement in the quality of care and services that we offer to patients. I was particularly touched when I wrote to Margaret after the meeting to thank her for her input, to receive a letter from her which thanked us as a group for allowing her to share her story with us and thereby empowering her to help to make things better for others who would find themselves in the same or similar circumstances. She contributed further by offering comment on the penultimate draft of the Patient Held Record and the finished product contains the amendments which she suggested.

Sadly, Margaret is no longer with us and we cannot share this evaluation of the Pilot of the Patient Held Record with her, but we are grateful to her husband and family for allowing us to pay this tribute to her. The legacy that Margaret would wish to leave is that the Patient Held Record would ensure better information for patients and better communication between members of the Multi-disciplinary Team providing their care.

Mark Twain wrote:

The miracle, or the power,
that elevates the few is to be
found in their industry,
application, and perseverance
under the prompting of a
brave, determined spirit.

With sincere gratitude to Margaret, a brave, determined spirit, I, on behalf of the Regional Patient Held Record Group would ask that the lessons to be learnt from this Pilot Study are taken seriously and, that through the leadership of the NICaN team, the Patient Held Record will be incorporated into the daily practice of all Professionals who are privileged to care for patients with a diagnosis of Cancer.

Irene Duddy,
Chairperson,
Regional Patient Held Record Group.

Foreword

The Cancer Services: Investing for the Future (Campbell) Report of 1996 was the impetus for the reconfiguration of cancer services in Northern Ireland. Emphasis was placed upon the need for an equitable, patient-centred approach yet it was apparent that best care could only be provided by ensuring that the cancer experts worked within teams. Such teams were to be based on the Cancer Centre / Cancer Unit model. However, there was a clear recognition that the quality of care delivered within Primary Care was pivotal to the overall quality of patient care. Communication between the various healthcare professionals involved in cancer care was, therefore, clearly identified as being critical in improving care.

In the fullness of time an electronic solution will be available which will allow seamless communication between patients and their many healthcare providers. That utopian situation is, however, a long way into the future. This evaluation of a Patient Held Record is an important milestone on the way to electronic utopia.

The report highlights the clear need of patients for information; the need for accurate and timely communication by one healthcare professional of another's intervention; and the need for accuracy of communication between a healthcare professional and the patient or their immediate carer. There is, however, evidence of reluctance to use a PHR to help solve some of the challenges. This reluctance stems from concerns about confidentiality; time resources; usefulness of the product and discomfort on the part of the healthcare professionals at patients having access to uncensored information.

Undoubtedly, concerns about confidentiality are rightly embedded within all healthcare professionals. However, a PHR is a patient-owned document and the patients in this survey did not see any threat to their care or information from the use of the PHR.

Time resources, product usefulness and professional discomfort are issues to be examined by Cancer Teams in their development process. That clinicians now work so effectively in teams is a testament to their enthusiasm of the recommendations of the Campbell Report. User Participation in team development is a further opportunity for the teams to adapt to new challenges and those solutions, which the teams themselves provide, are those which will be relevant and sustainable.

In summary, therefore, I am heartened by the findings of this report. Its publication, shortly after the introduction of the Northern Ireland Cancer Network, is timely. I would recommend to the Cancer Teams, working with their User Representatives, to determine how they best address the issues of timely and accurate information sharing and patient information access. A Patient Held Record may be a sound means to meet these new challenges.

Gerard Daly

Contents

Acknowledgment

Foreword

Abbreviations 8

Executive summary 9

Literature review:

Introduction 13

Other areas of Patient Held Record (PHR) use 14

Advantages of the PHR in Cancer Care 14

Disadvantages of the PHR in Cancer Care 17

Design and format of PHRs 19

Staff Involvement and Education 19

Conclusion 20

Method:

Background to PHR study 22

Legal and ethical issues 23

Format of PHR 23

Patient sample 24

Staff sample 24

Questionnaire design 24

Analysis 25

Results:

Patient questionnaire results 26

Staff questionnaire results 31

Document Checklist results 36

Discussion 38

Limitations 47

Conclusion		48
Recommendations		50
References		52
Appendices:		54
Appendix 1	**Cancer Units**	55
Appendix 2	**Staff Questionnaire**	56
Appendix 3	**Patient Questionnaire**	61
Appendix 4	**Document Checklist**	66
Appendix 5	**Membership of Working Group**	68
Appendix 6	**Patient Held Record Group**	69

List of Tables

Table number	Title	Page number
1	Patient diagnosis	26
2	Areas in which Patients lived	26
3	Results of how often the Patients carried the PHR	27
4	Other occasions when the PHR was used	28
5	Patients' agreement with issues regarding the PHR	28
6	Additional comments regarding features of the PHR	29
7	Comments regarding the 'Your Diary' section of the PHR	30
8	Patients' views on how the PHR could be improved	30
9	Patients' comments on the PHR	31
10	Professionals' views on how helpful the PHR was regarding various issues	32
11	Advantages of using the PHR	33
12	Disadvantages of using the PHR	33
13	Ideas on how the design of the PHR could be improved	35
14	Comments regarding the value of the PHR in Cancer Care	35
15	Suggestions on how the process of using the PHR could be improved	36
16	Quality of information written in the PHR	36

List of Graphs

Graph number	Title	Page number
1	Hospitals from which Patients were issued with PHRs	27
2	Patient satisfaction with features of the PHR	29
3	Doctors' and Nurses' views of the PHRs	32
4	Professionals' satisfaction with the features of the PHR	34
5	Individuals who most often completed the PHR	37

Abbreviations

GP	General Practitioner
NHSSB	Northern Health and Social Services Board
PHR	Patient Held Record
WHSSB	Western Health and Social Services Board

Executive Summary

Introduction

One in three people will be affected by cancer at some stage in their lives (Macmillan Cancer Relief, 1999). An individual's life is transformed by the diagnosis of cancer as they are suddenly faced with a new world with many important choices to make (Macmillan Cancer Relief, 1999).

It has been suggested that increasing specialisation in hospital practice and the expanding team membership in primary care has resulted in a tendency for fragmentation of care (Drury et al, 1996). When care delivery is fragmented there is the potential that insufficient information about the patient's treatment and care will be available to professionals involved in the patient's care, not to mention the patients themselves.

The Patient Held Record (PHR) is an informal record completed by Health Professionals and carers at primary, secondary and tertiary level. It is owned by the patient and presented to hospital and community staff for completion at each attendance. It includes information on such things as the patient's diagnosis, treatment and what support is available to them.

The PHR was designed for two main reasons:

1. To improve communication with patients and their carers.
2. To improve communication between health care professionals in all care settings.

Method

The sample population for the study consisted of all new patients presenting with solid cancer tumours (i.e. bowel, breast and lung) at any of the six cancer units (Appendix 1) in Northern Ireland between the 1st January 2002 and the 31st March 2002.

Questionnaires were designed to evaluate the overall effectiveness of the PHR (Staff questionnaire and Patient questionnaire) (Appendices 2 & 3 respectively), while a 'Document Checklist' (Appendix 4) was drawn up to evaluate the accuracy of the completion of the PHR. Statistical analysis of the questionnaires and 'Document Checklists' was performed using the Statistical Package for Social Sciences, while qualitative responses were analysed using thematic analysis (Burnard, 1996).

Key findings

Patient responses

- One hundred and twelve questionnaires were posted to all patients who accepted a PHR. Fifty questionnaires were returned resulting in a 44.6% response rate.

- Sixty one per cent (n=30) of respondents were female, while 39% (n=19) were male.

- Eighty one per cent of patients stated that the PHR made them feel better informed about their situation, while 77% (n=38) said that it helped them understand their illness/treatment.

- Almost three quarters (71%) of the patients felt that the PHR enabled/reminded them to ask questions about their condition, however, 60% (n=29) of patients stated that it did not remind them to take their medication.

Professional responses

- One hundred and ninety five questionnaires were distributed to staff working in the six hospitals involved in the study. Ninety four questionnaires were returned, of which 40 were completed, resulting in a 20% response rate.

- Over half of the professionals who responded (54.5%) felt that the PHR was a valuable asset to patient care. However, only 23% (n=7) of the professionals felt that there were advantages in using the PHR, e.g. improved inter-professional communication.

- Eighty one per cent (n=30) of professionals felt that there were disadvantages in using the PHR, e.g. time consuming and repetitive record keeping.

- Twenty two professionals felt that the PHR increased initial consultation time, while 51% (19) of professionals felt that they required additional education regarding the PHR.

Document checklist

- Six PHRs were assessed using the 'Document Checklist'. In all of these PHRs the recorded information was clearly written, accurate, up-to-date, comprehensive, easy to understand and completed in the correct place.

Recommendations

- Although some disadvantages of using the PHR have been pointed out, overall it would appear that the introduction of an oncology PHR has the potential to bring many benefits to cancer care.

- During a consultation/hospital appointment professionals should ask the patient for their PHR. It is important that the patient does not perceive the professional to be disinterested in the PHR, or feel that the professional does not have enough time to complete the PHR. By doing this the patient would therefore be encouraged to use the record.

- Although it is important that professionals complete the PHR, they must exercise caution so as not to cause any unnecessary worry to the patient or their loved ones. Therefore, they should not write anything in the PHR, which they would not discuss openly with the patient.

- Additional education regarding the benefits of the PHR should be provided for professional staff. This training could be in the form of study days, workshops or seminars Such education may highlight the benefits that PHRs bring to cancer care, so

that professionals will be more likely to see the extra time and paperwork required as being worthwhile, and will therefore be more likely to use the PHR.

- Professionals should be encouraged to use the PHR to communicate with other colleagues involved in the patient's care, as this is essential to obtain maximum benefit from the PHR.

- Following on from the previous recommendation it is important that all members of the multidisciplinary team, not just doctors and nurses, involved in the patient's care use the PHR. Other professional colleagues include therapeutic radiographers, physiotherapists, occupational therapists, social workers, chaplains, dietitions, speech and language therapists and pharmacists.

- The PHR should be offered to patients at their first doctor/hospital appointment after initial diagnosis. However, if they do not accept the PHR at this stage they should be made aware of its availability while in hospital.

- The research found that patients over the age of 60 years were less likely to 'always' carry the PHR and more likely to 'never' carry the PHR than those under 60 years. Therefore patients aged over 60 years should receive some form of encouragement to use the PHR, thus taking a more active role in their health care.

- When a patient accepts a PHR a coloured sticker should be put on their Medical Notes (Hospital and G.P.). Consequently, when the professional refers to the patient's notes at a consultation/hospital visit, they will be reminded to ask the patient for their PHR.

- The value of the PHR to the patient should be communicated to the multi-professional team, with the aim of encouraging them to complete the patient's PHR.

Literature Review

Introduction

One in three people will be affected by cancer at some stage in their lives (Macmillan Cancer Relief, 1999). An individual's life is transformed by a diagnosis of cancer as they are suddenly faced with a new world with many important choices to make (Macmillan Cancer Relief, 1999).

Cancer patients and their families crave information about their diagnosis and treatment but are often uncertain about what to ask and unhappy with the information they receive (Alcock et al, 2000). Effective communication is also of central importance to cancer patients and their carers to enable them to make informed choices. However, the efficacy of communication is a further source of dissatisfaction amongst patients (Alcock et al, 2000).

Increasing specialisation in hospital practice and the expanding team membership in primary care has resulted in a tendency for fragmentation of care (Drury et al, 1996). A study by Cornbleet (1996) showed that during the course of their illness, cancer patients see an average of 36 doctors (ranging up to 98) though they subsequently only remember seeing an average of six. This highlights the difficulty of maintaining rapid and accurate communications (Cornbleet, 1998). Primary care teams often feel that information from hospitals reaches them too slowly, making it difficult for them to offer appropriate support and advice to patients whose needs are changing rapidly (Cornbleet, 1998). Such poor communication and lack of information can compound the cancer patient's anxiety about their condition and complex treatments (Hayward, 1998). Patients' rising expectations have also meant that they are more likely to want access to information and to participate in decision making (Drury et al, 1996).

The Patient Held Record (PHR) is an informal record completed by professionals and carers at primary, secondary and tertiary level. The PHR is owned by the patient and presented to hospital and community staff for completion at each attendance. It includes information on the patient's diagnosis, treatment, support groups etc. PHRs have been used to improve

communication between and within levels of care, and to promote patients' involvement in their own care (Drury et al, 1996).

Other areas of PHR use

PHRs were first used in the 1970s and have proved successful in several areas of health (Drury, 1998). In paediatric oncology a parent-held record, or shuttle sheet, appears particularly valuable when a child is being treated or assessed at more than one institution, or by multiple health care workers (Stevens, 1992). Such records were introduced to paediatric oncology in response to issues raised by parents and professionals (Hooker & Williams, 1996). These records have now become an accepted part of the services provided for family members and professional partners in shared care (Hooker & Williams, 1996). Potential drug errors are reduced and correspondence required for patient care is decreased. The record acts as a diary and treatment planner for the patient's family and hospital staff, it supplements the hospital's medical data, is easily replaced if lost, and is inexpensive (Hooker and Williams, 1996).

Also in paediatric services, the immunisation record has proved accurate, with 85% agreement between the parent-held record and the immunisation record (Fierman et al, 1996). Immunisation records seem to be well maintained and several studies report high levels of acceptability, accuracy and availability on request (Bailey et al, 1994 & MacFarlane, 1991).

The co-operation card has been used in obstetrics for many years to record core physical data in defined fields, such as blood pressure, foetal heart rate and fundal height. It is designed to record progress of normal pregnancy and document early adverse signs in a standardised, agreed format. The woman can therefore access care wherever she is. In obstetrics women using a PHR reported higher satisfaction with their care, and felt more information was given to them than those not using the PHR (Forbes et al, 1996).

In mental health care the idea of a PHR has been slower to develop, but is now recognised as being beneficial both in aiding user involvement in mental health services, and for the co-ordination of care (Hannigan & Stafford, 1997). Previous studies in this area have shown PHRs to be successful, and helpful to both service users and providers (Balazs and Reuler, 1991).

Advantages of the Patient Held Record in cancer care

A number of studies have shown that there are advantages of using the PHR in cancer care (Drury et al, 1996; Finlay and Wyatt, 1998). Such advantages are outlined below.

Cancer patients are frequently on complex medication, and changes in medication are not always communicated between the various professionals involved in the patient's care (Finlay and Wyatt, 1998). Furthermore, patients may easily forget complex medication regimes. Studies have shown the PHR to be effective when used by the patient as an aide-memoir for current medication (Chetwynd et al, 2001; Drury et al, 1996; Finlay and Wyatt, 1998; Scottish PHRIEND, 1998).

As mentioned previously effective communication is often a problem in cancer care. The diverse needs of patients with cancer are met by an equally diverse number of professional carers (Drury et al, 1996). As the patient's condition deteriorates their feelings of loss of control and vulnerability may increase. As medical activity escalates, more lines of communication have to be opened with added potential for delay and mismanagement (Drury et al, 1996). Successful care depends on an awareness of these issues and an integrated response to them. The key to this is effective communication, which is facilitated by the PHR (Drury et al, 1996).

Frequent, accurate and up-to-date information on a patient's condition, treatment or outcome is often not available to their carer. Many primary care professionals find that their patient is 'lost' to secondary care from the point of referral. GPs sometimes get no feedback on progress, and if the patient visits them they are not 'up to speed' on their condition or treatment. Poor transfer of information has also been reported between hospital staff, GPs and hospice staff (Hayward, 1998). As a consequence of this the patients' needs cannot be adequately met. Therefore, frequent communication between these settings, even if brief, is vital to ensuring good, integrated and regular care (Primary Care Conference, 2001). The PHR would improve such communication between professionals, while also making it more inclusive of patients and their relatives (Drury et al, 1996).

The Northern and Yorkshire Regional Modernisation Programme created a PHR for use in cancer care. The aim of this project was to ensure that communication with the patient and their

family was open, honest and of the highest quality possible. They found that a particular strength of the PHR was improved communication, especially at the 'bad news' interview.

A randomised controlled trial was carried out by Scottish PHRIEND (1998) to examine whether having a PHR improved communication from the perspective of the patient. They concluded that one third of patients found it useful in transferring information between services. Specialist nurses and community-based staff were more likely to value the PHR as a communication aid for themselves than were hospital nurses and doctors.

The Committee for the Department of Health and Social Services and Public Safety Northern Ireland (2002) states that it can frequently take several months for newly diagnosed patients to become aware of the volume of organisations and support groups, which could be of use to them. The PHR would appear to be a solution to this problem by improving communication between health professionals and patients, and also by providing details of organisations, which exist to help cancer patients.

PHRs are particularly useful for patients who want to be involved in their own care (Cornbleet, 1998). The PHR can be used to empower the patient by involving them as an active partner in the planning of their care, rather than a passive recipient of their care over which they have no control (Chetwynd et al, 2001, Cross, 2002 & Jones, 1990).

It is not uncommon for patients suffering from cancer to hesitate or forget to raise questions during a consultation with a health professional (Finlay and Wyatt, 1998). Many patients use the PHR as an aid to asking important questions (Scottish PHRIEND, 1998). The patient holding the record is an empowering process that encourages their involvement in decision-making. The onus is placed on the patient to ask questions about their condition (www.nyx.org.uk/modern-programmes). Chetwynd et al (2001) state that the PHR has a positive impact on quality of care by enabling patients to prepare for meetings with health care staff.

Drury et al (1996) found that patients who used the PHR felt more involved in their care, while professionals who used the PHR claimed that they felt it made them more aware of the patients' feelings.

Some patients use the PHR as a therapeutic diary, disclosing their reflections on disease progression, and on encounters with health care personnel (Chetwynd et al, 2001). In a study carried out by Jones (1990) one District Nurse stated that by reading her patients' entries to the PHR she could understand the individuals' hopes and fears. They could then explore them together. Baldry et al (1996) state that almost one third of the patients in their study found using the PHR reassuring. Crack (1998) feels that relatives may also benefit from the PHR in the terminal stages of the illness by writing about their relative.

Giglio and Papazian (1986) suggested that the ultimate goals of the PHR are to improve continuity of care, to improve patient understanding of instructions, and to encourage patients to take a more active role in maintaining their health. Drury et al (1996) also found that the use of a PHR in cancer care facilitated continuity of care, particularly for out of hour's admissions, GP visits and health emergencies during holidays. Gilhooly and McGhee (1991) stated that another benefit of the PHR was that locum doctors would have access to records when making home calls and emphasised the importance of effective case notes being available at the time of consultation.

Other perceived benefits of the PHR suggested by researchers included monitoring changes in the patient's condition and symptoms, keeping track of appointments, recording blood test results, and providing a concise record to present to new staff as well as for future use (Scottish PHRIEND, 1998).

Disadvantages of Patient Held Record in cancer care

Confidentiality is clearly central to any discussion about PHRs (Gilhooly & McGhee, 1991). The debate about confidentiality is often about who has a right to know (Gilhooly & McGhee, 1991). Giving patients their own records might mean that family members, or even friends, might see the records and hence confidentiality may be breached (Gilhooly & McGhee, 1991). Of course it could be argued that if patients want their notes to remain secret then they would have to ensure that no-one in the household had access to them (Gilhooly & McGhee, 1991).

McGrievy (2002) suggested that consideration of what is actually recorded should be discussed and agreed with the patient and weighed against the possibility of records being stolen or accessed by others. In a study carried out by Liaw (1993), 47% (n=315) of GPs were concerned

about problems with confidentiality. Liaw (1993) also found that patients were mostly concerned with private and confidential information and felt that PHRs should not have "anything that the patient would not like to have included". However, it could be argued that for some patients having their notes at home has the potential to improve communication about their illness and treatment with family members (Gilhooly & McGhee, 1991). For example, the presence of notes may provide a focal point around which difficult topics could be broached (Gilhooly & McGhee, 1991).

Another possible disadvantage of using the PHR is that the patient may become scared or worried by information, which they read in the PHR regarding their condition. Fisher & Britten (1993) found that when 21 doctors were questioned about patients having the choice of viewing their own records, all of them expressed negative views that patients may be frightened, upset or misinterpret information.

Short (1986) believed that providing detailed information about their condition makes some patients anxious, and that non-disclosure is, for these patients, good management. Drury et al (1996) agreed with this and stated that health professionals using PHRs should not write anything in the record that they would not say directly to the patient.

Other studies have shown that patients may feel stigmatised or patronised by being given a PHR and may find it to be a constant reminder of their illness (Chetwynd et al, 2001 & Crook, 1998).

A final argument appearing in the literature against the use of PHRs is the extra time involved for health professionals. Often patients are not able to understand the content of the PHR and hence doctors need to take extra time to explain what they have written. Doctors may find it a culture shock to write things down in a language that patients will understand (Crack, 1998). In a study by Liaw (1993) it was found that 62% (n=315) of GPs expressed concerns with the extra paperwork involved with PHRs.

Another issue related to the use of the PHR is that some patients hesitate to ask health professionals to write in their record (Finlay and Wyatt,1998). This problem was also recognised by Crack (1998), who found that several patients were nervous about asking the oncologist to fill in the PHR, which had the potential to result in incomplete records and therefore less effective use of the PHR .

From the research evidence provided it appears that practical arguments against PHRs are not very compelling and certainly do not outweigh the arguments in favour of their use.

Design and format of PHRs

There has been considerable debate around the most appropriate structure and format of the PHR. Some studies have found the unstructured format to be most useful to patients and staff. Chetwynd et al (2001) believed that while patients should routinely be given a standard PHR, the same benefits may be obtained by encouraging patients to use a notebook to write down their thoughts, worries and questions, as well as keeping their own record of medication and appointments. They did suggest, however, that the patient should be offered the choice of a more structured PHR if they so desired, as in this way it would be patient-led rather than being constrained by a professional agenda. Crack (1998) also supported the use of an unstructured leaflet as she felt that such a format was less intimidating for patients.

Alcock (2000) on the other hand suggested that the use of a more structured format was beneficial and produced an Information File and Personal Health Diary based on the suggestions and views of cancer patients and a wide range of health professionals. This record contained communication/diary sheets for use by the patient, their family, and health professionals or carers, as well as pages for appointments, medication, addresses and telephone numbers. Finlay and Wyatt (1999) also supported this design. In their study to assess the preferred format of a PHR in cancer care they found that 60% of patients preferred the structured page lay out as they found it easier to complete.

All studies reviewed appeared to agree that patients favour a small sized (A5/A6) PHR, while loose pages in a soft plastic binder has also proved to be a convenient format (Crack, 1998, Finlay& Wyatt, 1999, Hayward, 1998, Jones, 1990).

Staff Involvement and Education

Several studies have shown that patients are more likely to use the PHR when they are encouraged to do so by the health professionals caring for them (Chetwynd et al, 2001, Giglio & Papazian, 1986).

A study by Giglio & Papazian (1986) strongly suggests that providers are the crucial factor determining the use of PHRs. By their beliefs and actions, overt and subtle, they strongly influence the acceptance rates. This study also suggested that health professionals would heavily influence the persistence in using records. Chetwynd et al (2001) were also of this opinion. They believed that when health professionals appear to be busy or distracted in using the PHR, the patients cease offering it at consultations. Therefore, to obtain the most from PHR use, many health professionals would have to change the way they deliver care. In particular they would have to actively encourage greater patient participation in the care delivery process (Giglio & Papazian, 1986).

It may be the case that health professionals require additional education regarding the benefits the PHR can bring to cancer care. Chetwynd et al (2001) suggested that such education of both professionals and patients may extend and enhance the use of the PHR. Cross (2002) agreed with this and felt that clinicians, in particular, need educating about the reasons to share data. Others feel that education about PHRs should be aimed at senior professionals so that they can pass on their knowledge to the more transient staff at junior levels (www.palliativecarescotland).

Conclusion

Patients with cancer are likely to have complex treatments involving several hospital departments, as well as primary care and community services. Therefore, effective communication often proves problematic for patients and health professionals (Centre for Health Services Research, University of Newcastle, 2001). The use of the PHR would appear to help counteract this problem and bring many advantages to cancer care, e.g. improve communication, remind patients of medication regimes, and help the patients to ask important questions (Chetwynd et al, 2001, Drury et al, 1996 & Finlay and Wyatt, 1996).

Several potential problems, however, have also been noted in the literature, e.g. confidentiality issues, extra time involved in completing the record, and, for the patient and their family, a constant reminder of the illness (Chetwynd et al, 2001, Finlay and Wyatt, 1998 & Gilhooly and McGhee, 1991).

There is still much debate surrounding the most appropriate format for the design and structure of the PHR. It is not universally agreed if such a record should be structured or unstructured. However, it is widely accepted that a smaller record is the most convenient for patients to carry (Crack, 1998, Finlay and Wyatt, 1999).

It is apparent that patients are more likely to use the PHR if encouraged to do so by the health professionals involved in their care (Giglio & Papazian, 1986). Therefore additional education may be necessary to inform professionals of the potential advantages of using the PHR (Chetwynd et al, 2001 & Cross, 2002). With such education and positive involvement of professionals, the PHR has the potential to be an extremely valuable aid to the patient, their relatives and all involved in their care.

Method

Background to the Patient Held Record Study

At the Northern Ireland Regional Oncology Workshop held in the WHSSB in 1998 the issue of PHRs was raised and Miss Duddy (Director of Nursing, Altnagelvin Hospital) was asked to chair a group to develop a record. The group comprised staff from Primary and Secondary Care (Appendix 5).

Mrs Margaret Irwin, a NHSSB patient attended one of the meetings and related her experience as a patient faced with a diagnosis of cancer. She also shared with the group her views on what a PHR should contain. Subsequent to this meeting Mrs Irwin read the draft PHR devised by the group and provided valuable comments on the record.

The PHR was designed for two main reasons:

1. To improve communication with patients and their carers.
2. To improve communication between health care professionals in all care settings.

The use of PHRs was thoroughly researched. Each Cancer Unit was invited to submit copies of PHRs and/or Cancer Information Leaflets they were currently using. They were also invited to forward any other information that they thought might assist the group in its work. Copies of PHRs were also obtained from hospitals in Great Britain.

After a number of years research and careful consideration the design of the PHR was concluded. However, its release was withheld to enable comparison to take place with a similar record that was being prepared by the Cancer Alliance in England. When the two versions were compared a high degree of commonality was found. The conclusion was that no alterations needed to be made to the local version. Eventually, in early 2000, the Campbell Commissioning Project was asked to oversee its introduction.

A group of staff from Primary and Secondary Care was convened (Appendix 6), and chaired by Mr Raymond McMillen, to introduce the PHR on a pilot basis.

An action plan was formulated which took into account recommendations made by the Project Board. The plan was to pilot the introduction through the issue of the PHR to new patients with

solid tumour cancers attending the Cancer Centre and Cancer Units for radiotherapy and/or chemotherapy.

The Project Board commissioned the University of Ulster to undertake the study. Dr Kate Sullivan and Miss Anne Devlin carried out the research.

Legal and Ethical Issues

The group sought clarification as to the legal status of the PHR as part of the process of planning for implementation and were advised that information contained within the PHR did not replace the main hospital/GP/therapy records. For legal purposes, such records would continue to be regarded as the main record. Should any discrepancies arise these should be clarified by reversion to the main hospital record. As the PHR is the patient's property the patient is responsible for its safekeeping and storage. In the event of the patient's death, the property would normally pass to their next of kin. All ethical principles in respect of research were adhered to throughout the study.

Format of the PHR

After two years the group concluded its design of the PHR. The record was submitted for scrutiny by the Plain English Campaign. It was approved by them and awarded their Crystal Mark.

The PHR was produced in two parts:

A blue A5 sized booklet (Personal Health Record)

This was designed to fit inside a handbag or pocket. It should be used by all staff to record treatment dosages, results, information for carers, contact numbers etc. Patients could also note questions that they would like to ask at their next hospital/medical consultation in the booklet.

A blue A4 sized booklet (Your Diary)

This is likely to be kept in the patient's home. It contains a patient diary, a list of organisations and services which provide support for patients and their carers, and a glossary of terms used in cancer treatment.

Patient sample

The sample population consisted of all new patients presenting with solid tumour cancers (i.e. bowel, breast and lung). From the 1st January 2002 the PHR was offered to these patients at their second attendance after initial diagnosis, in either the Cancer Centre or their Cancer Unit. The lead cancer nurse at each unit oversaw this. A record was kept of which patients accepted/declined the offer of a PHR. Only those patients who accepted the PHR between the 1st January 2002 and the 31st March 2002 were included in the study. Patients were encouraged to read and make comments in the PHR, and to make it available to anyone involved in their care.

Staff sample

The issue of the staff sample was discussed at the steering group meetings and it was decided that a total of 40 staff questionnaires would be sent to each Cancer Unit (i.e. Antrim Area Hospital, Altnagelvin Hospital, Belvoir Park Hospital, Craigavon Area Hospital and The Ulster Hospital, see Appendix 1) but that Belfast City Hospital, which is also the Cancer Centre, would receive 50 questionnaires. The questionnaires were then distributed by the Unit representative to all professionals working in cancer care in their Unit (i.e. Doctors, Nurses and Therapeutic Radiographers).

Questionnaire design

Questionnaires were designed to evaluate the overall effectiveness of the PHR.

The patient questionnaire (Appendix 3) covered the following areas:

- Patient demographics
- How useful patients found the PHR
- How useful the A4 diary was
- The design of the PHR
- GP use of the PHR
- Confidentiality issues
- Suggestions for improvement

Patients were also asked if they were willing to be contacted regarding this research, and were invited to complete a tear-off strip with details of their name and address.

The staff questionnaire (Appendix 2) covered the following areas;

- How useful staff found the PHR
- Advantages of using the PHR
- Disadvantages of using the PHR
- Altered consultation times
- Instructions on use
- Need for extra education
- Suggestions for improvement

In August 2002 all patients who had accepted a PHR were sent a patient questionnaire, while staff working with cancer patients in the six Cancer Units received staff questionnaires. A covering letter and stamp-addressed envelope accompanied each questionnaire. The covering letter informed the patient/member of staff of the purpose of the study and assured confidentiality of results. After four weeks a reminder letter was sent to all patients and staff.

A Document Checklist (Appendix 4) was also designed to evaluate how the PHRs were completed. The checklist examined the following areas;

- Was information accurate, up-to-date, sufficient?
- Were all sections used equally?
- Which professionals used the PHR?

Those patients who gave their name and address in the patient questionnaire were then contacted by a hospital representative and asked if their PHR could be examined using the Document Checklist.

Analysis

Statistical analysis of questionnaires and checklists was performed using the Statistical Package for Social Sciences (SPSS) Version 9.0, while qualitative responses were analysed using thematic analysis (Burnard, 1996, p.278) to reveal common themes.

Results

Patient Questionnaire Results

Questionnaires were posted to all 112 patients who had accepted a PHR. Fifty questionnaires were returned, resulting in a 44.6% response rate. Sixty one per cent (n=30) of the respondents were female, while 39% (n=19) were male. The ages of the respondents ranged from 32 years to 76 years, with a mean of 57 years.

The diagnosis of those patients who participated in the study can be seen in Table 1. It was found that approximately one third of respondents suffered from either breast or bowel cancer, while only one patient was diagnosed with lung cancer. Unfortunately fourteen individuals did not understand this question and responded by stating their prognosis, e.g. 'fair', 'good', etc.

Table 1 Patient Diagnosis

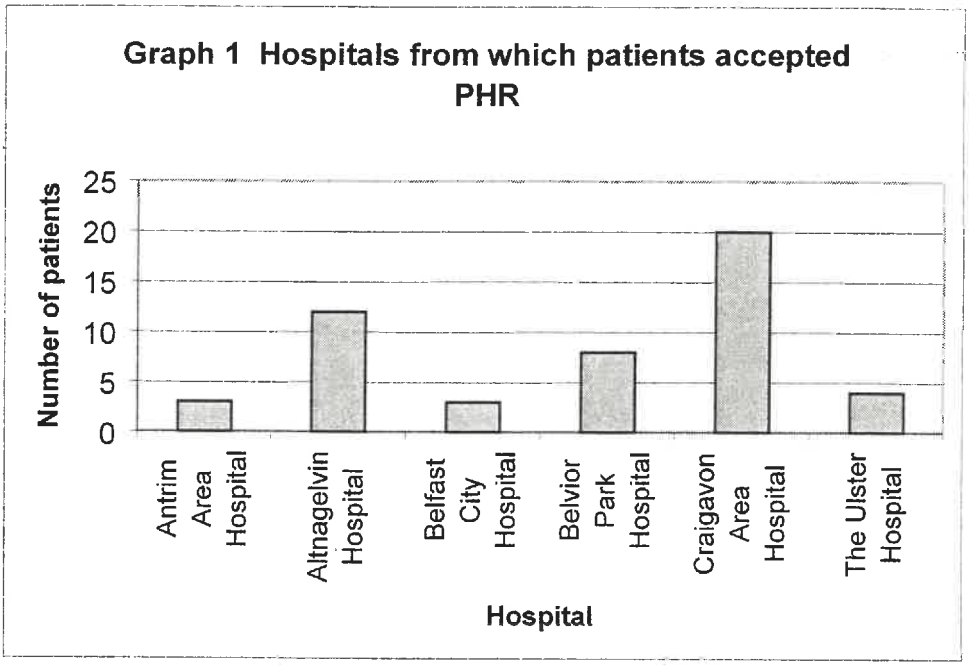
Diagnosis	No.	%
Breast	14	32
Bowel	16	34
Lung	1	2
Misunderstood question	14	32
Missing	5	-
TOTAL	50	100

Table 2 shows the geographical areas in which patients lived. Thirty per cent (n=15) of patients were from County Armagh, while only one patient was from County Fermanagh.

Table 2 Areas in which Patients lived

Area	No.	%
Belfast	5	10
Co. Antrim (other than Belfast)	4	8
Co. Armagh	15	30
Co. L.Derry	7	14
Co. Down	9	18
Co. Fermanagh	1	2
Co. Tyrone	9	18
TOTAL	50	100

The most common hospital from which the patients accepted the PHR was Craigavon Area Hospital (40%), while 24% of patients accepted the PHR from Altnagelvin Hospital (Graph 1).



Eighty six per cent of the patients (n=42) were given the PHR by a nurse, while 12% (n=6) received the PHR from a doctor. Only one patient was given the PHR by a therapeutic radiographer.

Forty five (92%) patients felt that the PHR was given to them at the most useful time. Of the four patients who felt that the PHR could have been given to them at a better time, two stated that they would have preferred to receive the PHR after surgery but before chemotherapy, while one patient simply stated that they would have liked to receive the PHR while still in hospital.

Table 3 shows how often the patients carried the PHR with them. It was found that only 8.5% of patients (n=4) 'never' carried the PHR with them. It is worth noting that one third of all patients who were given the PHR by a doctor 'always' carried it with them, while only 12.5% of those who were given the PHR by a nurse did so.

Table 3 Results of how often the patient carried the PHR with them

	No.	%
Always	7	15
Usually	4	9
Only for chemotherapy/radiotherapy appointments	32	68
Never	4	8
Missing	3	-
TOTAL	50	100

It was also interesting to note that 19% of patients who were younger than 60 years of age 'always' carried the PHR, while only ten per cent of those aged over 60 years did so. Similarly, only four per cent of those aged under 60 years 'never' carried the PHR, compared to 16% of those aged over 60 years.

The PHRs also appeared to have been used on a range of other occasions (Table 4). Sixteen patients stated that their District Nurse had used their PHR, while 15 patients' own GPs had made use of their PHRs. It was also found that 10 patients' 'out of hours GPs' had referred to the information in their PHRs.

Table 4 Other occasions when the PHR was used

Other occasions	No. Patients	%
District Nurse	16	31
Own GP	15	29
Out of hours GP	10	20
Other Hospitals	3	6
Family members	2	4
Home Care Nurse	1	2
Stoma Care Nurse	1	2
Patient on holiday	1	2
Can't remember	1	2
Own information on side effects	1	2

Patients were then asked whether they agreed or disagreed with a range of statements regarding the benefits of the PHR (Table 5).

Table 5 Patients' agreement with issues regarding PHR use

Issue	Agree	Disagree
Makes decisions about treatment easier	29	19
Makes me feel better informed about my situation	39	9
Helps me understand my illness/treatment	37	11
Makes me feel more in control of my situation	28	20
Reminds me to take my medication	19	29
Enables/reminds me to ask questions about my condition	34	14
Helps me to explain my illness to my family	26	22

These results are generally quite encouraging, however, it is disappointing that 60% of patients disagreed with the statement that the PHR reminded them to take their medication. When asked

about the phone numbers provided in the PHR it was found that 61% (n=30) of patients thought that these numbers were 'very useful', while 35% (n=17) stated that they were 'quite useful'. Only two patients felt the numbers were of little use. Seventy two per cent of male patients found the phone numbers to be 'very useful', while only 53% of female patients were of this opinion.

Graph 2 indicates that most patients were very satisfied with the features of the PHR. Additional comments on the features of the PHR are presented in Table 6.

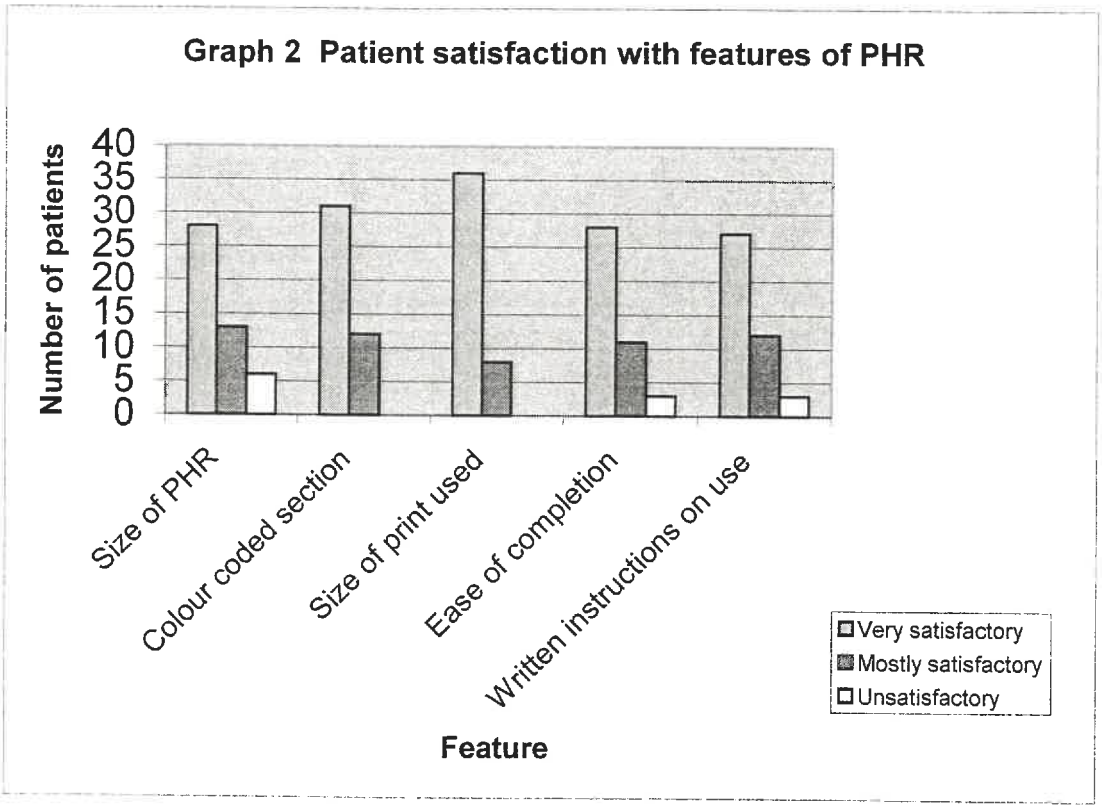


Table 6 Additional comments regarding the features of the PHR

Comment	Number of patients
Test result section not big enough	1
Very repetitive	2
Some blank pages would be useful	1
Diary section too cumbersome	1
Too much of a burden - Would rather just ask	1

Almost one third of the patients found the 'Your Diary' section to be 'very useful', while 46% (21) of patients thought it was 'quite useful'. Unfortunately 22% (10) patients felt that this section of the PHR was 'of little use' to them, while one patient felt that it was 'not useful at all'.

The patients expressed a range of views when asked if they had any comments regarding the 'Your Diary' section of the PHR (Table 7).

Table 7 Comments regarding the 'Your Diary' section of the PHR

Comment	Number of patients
Patient already had all the information they needed	2
Did not use it	2
Too big	2
Used it to help with research	1
Could express feelings in PHR	2
Helped me to remember the side effects	2
Useful to the nurses	1
Mainly used to keep blood results	1

None of the patients stated that they had any worries concerning the confidentiality of information written in the PHR. One patient stated that 'you are responsible for your own record' while another felt that 'there are only blood results in it – so there is no need to worry'.

When the patients were asked how they felt the PHR could be improved a range of suggestions were given (Table 8).

Table 8 Patients' views on how the PHR could be improved

Comment	Number of patients
Smaller size	3
Information should be summarised	2
A lot of pages did not apply to me	2
Should be checked by nurses	1
Should be given to patient after surgery, but before chemotherapy	1
Section for nurses to jot down notes which I could read later	1
Information should be regularly added on advanced cancer treatments	1

Finally the questionnaire asked the patients if they had any other comments regarding the PHR (Table 9).

Table 9 Patients' comments on the PHR

Comment	Number of patients
No staff ever asked for/used the PHR	4
Do not want to be reminded of cancer	2
Very useful	1
Good when used as a medication reminder	1
Would have liked it before chemotherapy	1
Too long	1
Need time to discuss with nurse	1

As seen from Table 9 four patients stated that no member of staff ever asked for the PHR. Two patients felt that they did not want to be reminded of their cancer.

Staff questionnaire results

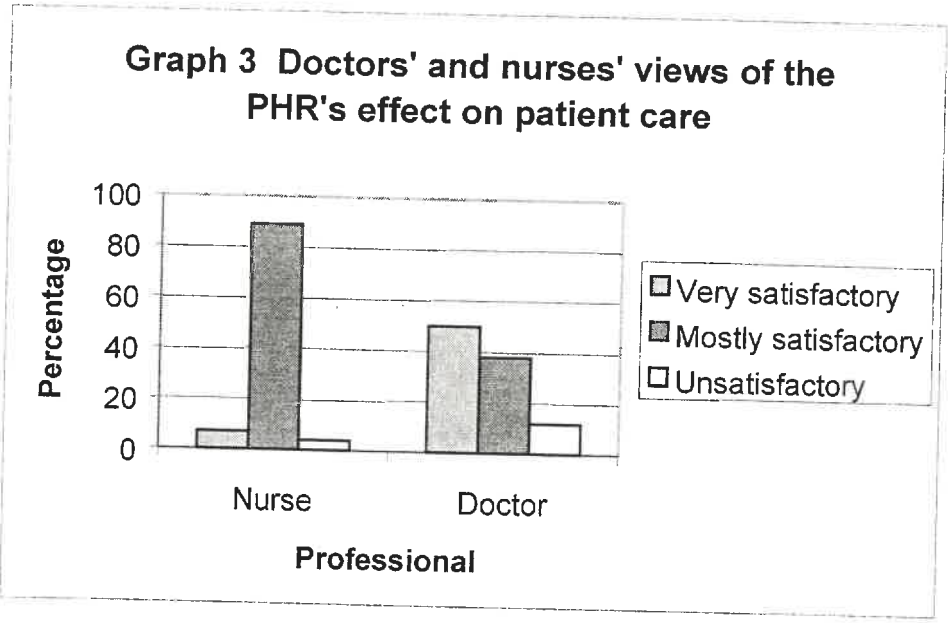
One hundred and ninety five questionnaires were distributed to staff working in the six hospitals involved in the pilot study. Ninety four questionnaires were returned resulting in a 48.2% response rate. Of those questionnaires returned 54 were not completed due to the respondent's lack of knowledge/experience regarding the PHR. Therefore, a total of 40 questionnaires were completed (20%).

Four respondents were male while 36 were female. Sixty five per cent (n=26) of respondents were nurses, while 15% (n=9) were doctors. The remaining respondents consisted of a physiotherapist, social worker, dietition, pharmacist and therapeutic radiographer. Eighty three per cent of the professionals who responded had been qualified for at least 10 years (maximum: 30 years, minimum: 3 years, mean: 16.3 years).

When asked what effect they felt the PHR had on patient care 18% (n=7) professionals stated that it had a positive effect, while five per cent (n=2) felt it had a negative effect. Seventy five per cent (n=30) of professionals stated that the PHR had no effect on patient care.

Four individuals commented that the patient did not use/was not interested in the PHR. Two professionals stated that the information in the PHR was useful to patients. One individual felt that the PHR was useful for communicating with patients in the community. It was also suggested by one professional that the PHR increased anxiety in some patients and relatives, while another felt that any information required by the patient could be provided by the nurse.

It is interesting to note that 50% (n=4) of doctors who participated in the study felt that the PHR had a positive effect on patient care, compared to 7.7% (n=2) of nurses. Thirty eight per cent of doctors felt that the PHR had no effect on patient care, compared to 88.5% of nurses (n=23) (Graph 3).



The table below presents the professionals' views of how helpful the PHR was regarding a range of issues.

Table 10 Professionals' views of how helpful the PHR was regarding various issues

	Extremely helpful (%)	Somewhat helpful (%)	Not very helpful (%)	Not helpful at all (%)
Patient knowledge	4 (10)	25 (64)	9 (23)	1 (3)
Professional knowledge	2 (5)	13 (33)	21 (54)	3 (8)
Recording of patient details	3 (8)	22 (56)	12 (31)	2 (5)
Patient-professional communication	3 (8)	15 (39)	19 (50)	1 (3)
Inter-professional communication	2 (5)	15 (39)	18 (48)	3 (8)
Compliance with medical instructions	0	13 (36)	17 (47)	6 (17)
Encouraging patient self-reliance	0	17 (47)	17 (47)	2 (6)

Seven professionals felt that there were advantages to using the PHR. Such advantages are shown in Table 11.

Table 11 Advantages of using the PHR

Advantage	Number of professionals
Useful to use to access patient information if necessary	2
Aids inter-professional communication	2
Useful for patients to have their own record	2
Empowers patient to deal with their illness	1

Table 12 Disadvantages of using the PHR

Disadvantage	Number of professionals
Time consuming	7
Too big	7
Repetitive record keeping	4
Patients felt obliged to accept it	4
Too much information in PHR	3
Forgetting/losing notes	3
Nowhere to record blood tests	2
More pressure for patients	2
Cumbersome for patients	2
Not enough time for paperwork	2
Reading poor prognostic information may increase patient anxiety	2
Not enough space for nurses	1
Difficult for patient to read and complete	1
Not compliant for every discipline	1
Constant reminder of cancer	1
Confidentiality issues	1
Notes in PHR not always kept up to date	1

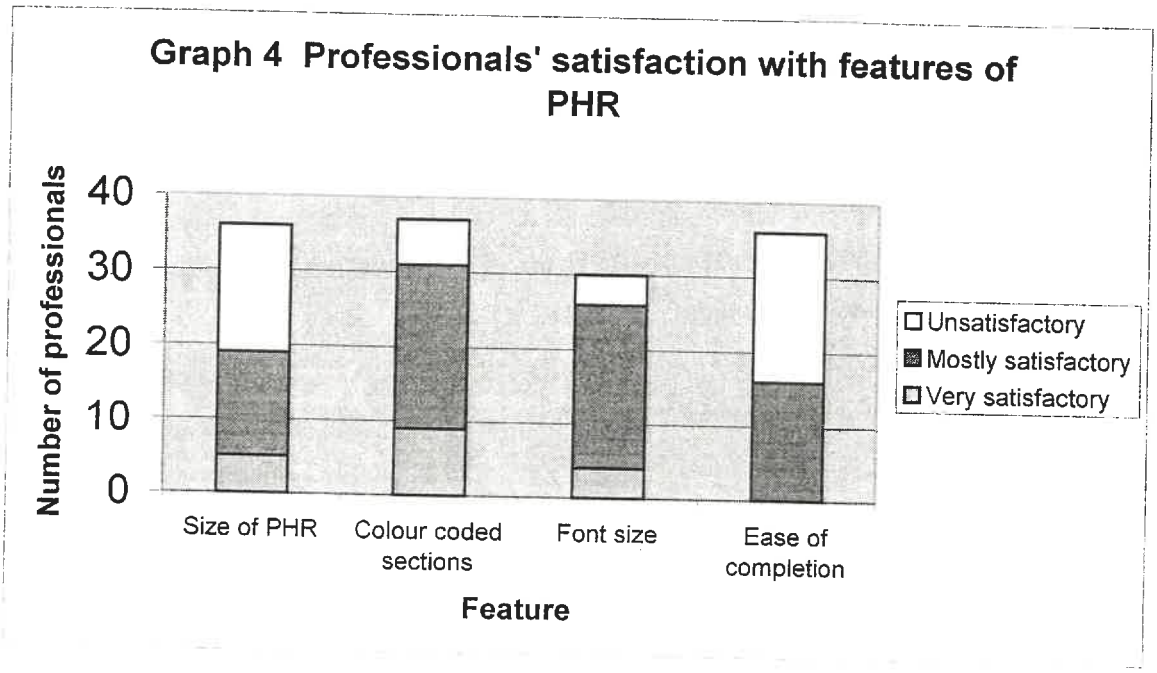
Almost three quarters (n=22) of professionals felt that the use of the PHR altered initial consultation time. The mean time by which this consultation was said to increase was 17.5 minutes. (minimum: 2 minutes, Maximum: 45 minutes). Nine (35%) professionals felt that the PHR increased subsequent consultation times. The mean increase in time here was 6.6 minutes (minimum: 3 minutes, maximum: 20 minutes).

Information on how professionals were to complete the PHR was provided on pages five and six of the booklet. When asked what they thought of this information nine per cent (n=3) of professionals stated that it was very helpful, while 70% (n=23) felt that it was quite helpful. Twenty one per cent (n=7) of professionals felt that it was not very helpful. When asked to comment on this information one professional stated that the information made them more aware of the PHR, while another remarked that it was very clear and concise. However, one

individual felt that information was not specific enough. Views such as these may indicate a need for additional staff training regarding the use of the PHR.

Fifty one per cent (n=19) of the respondents stated that additional professional education regarding the PHR was required. Four professionals believed that such education might encourage the use of the PHR. One individual felt that only non-nurse professionals required additional education, while another individual stated that the PHR was self-explanatory and no further education was required. It was also suggested that professionals should receive such education before implementation of the PHR into the clinical area, as this additional education may increase professionals' confidence in using the PHR.

The questionnaire also evaluated the design/format of the PHR (Graph 4). Fourteen per cent (n=5) of professionals were 'very satisfied' with the size of the PHR, while 39% (n=14) were 'mostly satisfied' with this feature. Unfortunately, almost half (n=17) of the professionals felt that the size of the PHR was 'unsatisfactory'. One quarter of professionals were very satisfied with the colour-coded sections, while 59% were 'mostly satisfied' with this feature. Over three quarters (n=28) of professionals were 'mostly satisfied' with the font size used in the PHR. It was disappointing to find that over half (n=22) of professionals found the ease of completion to be unsatisfactory'.



The ideas provided by professionals on how the design of the PHR could be improved are presented in Table 13. It is seen from this table that 50% of these comments state that the PHR should be smaller.

Table 13 Ideas on how the design of the PHR could be improved

Idea	Number of professionals
Smaller	13
Should be similar to 'Your Chemotherapy Record'	2
Too much detail	2
Section identification should be used	2
Diary format	1
Hospital's own PHR easier to use	1
More details on side effects	1
More space for treatment details	1
Space for consultations with doctors	1
Space for blood results	1
Continuation pages more easily available	1

Over half (54.5%) of the professionals felt that overall the PHR was a valuable asset to patient care. It is worth noting that 12 (50%) of the 24 nurse respondents felt the PHR was a valuable asset to patient care, while all six doctors were of this opinion.

When the professionals were asked to comment on the value of the PHR in cancer care a range of viewpoints emerged (Table 14).

Table 14 Comments regarding value of PHR in cancer care

Comment	Number of professionals
More concise/too much information	4
Need continuity of use	2
Must be used correctly	2
Too much information for patient to fill in	2
Not all patients want to use PHR	2
Format should be changed	2
Not useful as only nurses are using it	1
Test result sections need improving	1
Useful to have all information together	1

The final question on the questionnaire asked professionals how they felt the process of using the PHR could be improved (Table 15). Four individuals felt that it should be simplified, while one individual felt that the PHR should be distributed from more than one point. One individual felt that the PHR should be issued to all patients rather than asking them if they

wanted it, as asking the patient to make another decision at this time may cause them additional stress.

Table 15 Suggestions on how the process of using the PHR could be improved

Comment	Number of professionals
Process could be simplified	4
Better training for staff	3
Smaller size	2
More than one point where PHR is given out	2
Encourage patients to remember to bring PHR to appointments	2
Issued to all patients – another decision leads to stress	1
Combine with hospital's own PHR	1
Patients should request it – no pressure	1
Put the contact numbers at the front	1
Coloured sticker on patient notes to indicate that they have a PHR	1
Staff should ask patients for their PHR	1

Document Checklist Results

Six PHRs were assessed using the Document Checklist. All of these PHRs had been used. Doctors (Consultants) had written in two of the PHRs, while GPs had written in three of the PHRs. Nurses had completed five of the PHRs, while four patients had written in their PHRs. Only one PHR contained information written by a family member. The average length of time the PHRs were used was 13.8 weeks (maximum: 23 weeks, minimum: 5 weeks).

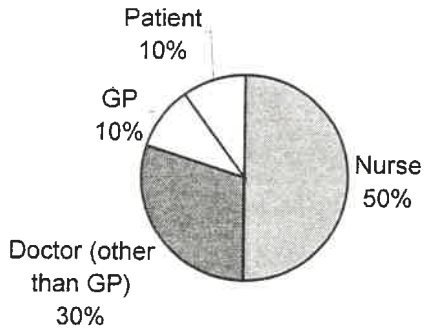
When the quality of the information written in the PHRs was assessed the findings were quite positive (Table 16).

Table 16 Quality of information written in the PHR

Was the recorded information	Yes	No	Sometimes
Clearly written?	5	0	1
Accurate?	5	0	0
Up-to-date?	6	0	0
Comprehensive?	5	0	0
Easy to understand?	5	0	0
Completed in the correct place?	6	0	0

In five of the six PHRs all sections of the PHR were used (1 missing). Again, in five PHRs the 'chemotherapy section' was used most, while in one record the 'medication section' was used most often. Unfortunately, however, in four cases 'all professionals' did not use the PHR. The nurses used the PHRs most often (Graph 5).

Graph 5 Individuals who most often completed the PHR



The Document Checklist then assessed what the professionals used the PHR for. It was found that five professionals used the PHR to 'communicate with other professionals', while four used it to 'give a written explanation to the patient'. Three professionals used the PHR to 'record dates of further investigation/treatment', while only one professional used the PHR to 'make appointments'.

In all six PHRs there appeared to have been enough room for the information required.

Discussion

In this study patients who completed the Patient Questionnaires were felt to be representative of the overall population of cancer patients in Northern Ireland, due to variations in age, cancer type, hospitals attended and areas in which they lived.

Although the professionals who completed Staff Questionnaires consisted predominately of nurses and doctors, this may in fact be representative of the overall number of professionals who use the PHR. It was also discovered that 90% (n=36) of the professionals who responded were female. This may be explained by the higher percentage of females working in healthcare, particularly in nursing roles. It was reassuring to find that the majority of professionals who returned the questionnaires had at least 10 years post-qualification/registration experience, with an overall mean of 16.3 years experience. This may imply that professionals who are experienced in healthcare recognise the importance of the PHR in cancer care and therefore saw the importance of completing and returning the questionnaires.

It was encouraging to find that 92% (n=45) of patients felt that the PHR was given to them at the most useful time. The time of introduction of the PHR in this study was at the patients' second attendance (after initial diagnosis) in either the cancer centre or at their cancer unit. Such a view is supported by the Committee for the Department of Health and Social Services and Public Safety (2002), which states that it can frequently take several months for newly diagnosed patients to become aware of the volume of organisations and support groups which are available to them. They feel that the PHR offers a solution to this problem in that it improves communication between health professionals and patients whilst also providing details of organisations that exist to help cancer patients.

Eight per cent (n=4) of patients felt that the PHR was not given to them at the most useful time. Two of these patients stated that they would have liked to have received the PHR after surgery but before chemotherapy.

Eighty six per cent of patients (n=42) stated that they were given the PHR by their nurse compared to only 12% (n=6) who were given the PHR by their doctor. This would correspond with the percentages of various professionals returning the questionnaires, as 65% of responses

were from nurses, while only 12% were from doctors. These figures would imply that of all the professionals working in cancer care the nurse is the most likely to use the PHR.

Fifteen per cent of patients stated that they 'always' carried their PHR with them, while nine per cent said that they 'usually' carried their PHR with them. It was slightly disappointing however, to find that over two thirds (68%) said that they only took their PHR to chemotherapy/radiotherapy appointments, while nine per cent said that they 'never' carried it. Giglio and Parpazian (1986) state that the provider of the PHR is a crucial factor in determining the use of the PHR. They suggest that health professionals can strongly influence not only the acceptance rates, but also the persistence in using the PHRs. The results of this study support such an opinion, as one third (33%) of all patients who were given the PHR by a doctor 'always' carried it, while only 12.5% who were given the PHR by the nurse did so. Chetwynd et al (2001) therefore feel that to obtain the most from PHRs many health professionals will have to change the way they deliver care.

There also appeared to be a relationship (however, this was not statistically significant) between the age of the patient and how often they carried the PHR. Ten per cent of over-60s 'always' carried the PHR, while 19% of under-60s 'always' carried the PHR. Similarly, 16% of over-60s 'never' carried the PHR, compared to only four per cent of under-60s. One explanation for this may be that younger patients may take a more pro-active role in their healthcare, compared to older patients who may be more inclined to leave all decisions regarding their health to health professionals.

It was encouraging to find that the PHRs had been used in a range of occasions other than for the purpose of hospital visits. Sixteen patients stated that their District Nurse had used their PHR, while fifteen patients' own GPs had used it. The benefit here is that the District Nurse and GP would have access to information regarding the patient's health written in the PHR by hospital staff, e.g. radiographers, which otherwise may not have been available to them. They will also have the opportunity to record any notes, which they feel would be important for future reference.

Ten patients stated that their PHR was used by an 'out of hours GP', while three patients claimed that 'other hospitals' referred to their PHR. Again the obvious benefit here is that the patients' medical notes were immediately available to such staff, and this would not have been

possible if it were not for the PHR. It was also gratifying to find that two patients' families had referred to the PHR, while another patient had 'packed' the PHR when going on holiday. These findings are similar to those of Drury et al (1996) and Gilhooly & McGhee (1991) in that they demonstrate a much-welcomed increase in continuity of care.

When the patients were given a list of statements about the uses/value of the PHR the answers were generally very positive. Eighty one per cent of patients stated that the PHR made them feel better informed about their situation, while 77% said that it helped them understand their illness/treatment. While patients were not directly asked the reasons for this it was probably due to the fact that the PHR provides valuable information for the patient, such as a glossary of terms used in cancer care, along with the fact that the patients can read the notes that the health professionals make regarding their condition.

Due to this increased knowledge about their illness and treatment, it was not surprising to find that the majority of patients felt that the PHR made making decisions about their treatment easier, helped them to explain their illness to family members and made them feel more in control of their situation. Giglio & Papazian (1986) advocate that an ultimate goal of the PHR is to improve patient understanding of instructions, thus encouraging them to take a more active role in maintaining their health. The findings from this study would suggest that the PHR has been successful in this respect.

Finlay & Wyatt (1996) state that it is not uncommon for patients suffering from cancer to hesitate or forget to raise questions during a consultation with a health professional. It was reassuring to find that almost three quarters (71%) of patients stated that the PHR enabled/reminded them to ask questions about their condition, however, it may also be because a list of 'questions you may like to ask' was included in the PHR. This list suggested a range of questions which the patient may like to ask a health professional, e.g. 'What are the side effects of my treatment?' and 'What will happen after my operation?'.

It was surprising to find that 60% of patients stated that the PHR did not remind them to take their medication. Perhaps such patients preferred to use the PHR merely as a source of information and so did not rely on it as a medication reminder. This is contrary to the results of a number of previous studies, which showed the PHR to be effective when used by the patient

as an aide-memoir for current medication (Chetwynd et al, 2001; Drury et al, 1996; Finlay & Wyatt, 1996, & Scottish PHRIEND, 1998).

A similar list of issues was presented to the health professionals and they were asked how beneficial they felt the PHR was regarding them. Overall, the professionals' response to this question were somewhat disappointing. Sixty two per cent of professionals felt that the PHR was either 'not very helpful' or 'not helpful at all' regarding professional knowledge. This is perhaps not surprising as professionals working with cancer patients should already have a broad knowledge of cancer care. However, the PHR would be expected to greatly increase the professionals' knowledge of individual patient's medical histories.

It was also disappointing to find that no professional felt that the PHR was 'extremely helpful' regarding patient compliance with medical instructions, while 36% felt that it was 'somewhat helpful' for this purpose. This corresponds to the results from the patient questionnaires, which were also of this opinion. It may therefore be the case, that some form of medication reminder should be incorporated into the PHR. Fifty three per cent of professionals and 56% of patients felt that the PHR was 'not very helpful' or 'not helpful at all' in increasing patient/professional communication and inter-professional communication respectively. This is quite disappointing as one of the desired goals of the PHR is to increase communication, not just between professionals themselves but also between the patients and the professionals.

Another aspiration of the PHR is to increase the self-reliance of cancer patients, however, less than half (47%) of the professionals felt that the PHR was 'somewhat helpful' regarding this issue, while no-one felt that it was 'extremely helpful'.

It was reassuring, however, to find that 74% of professionals deemed the PHR to be at least 'somewhat helpful' in increasing patient knowledge, while 64% of professionals thought that the PHR was at least 'somewhat helpful' in recording patient notes.

The PHR provided a list of phone numbers and addresses, which may be useful to cancer patients, e.g. hospitals, hospices, voluntary organisations and advice help-lines. These numbers appeared to be greatly appreciated by the patients, with 61% stating that the numbers were 'very useful', while 35% felt that they were 'quite useful'. Seventy two per cent of male patients felt that the phone numbers were 'very useful' compared to only 53% of females. One possible

explanation for this may be that females are more likely to ask questions in a face-to-face situation with health professionals, while males may choose to take a more anonymous approach to obtaining the desired information.

When asked about various aspects of the PHR format, the responses were again found to be very positive. The majority of patients felt that the size of the PHR, colour coded sections, size of print, ease of completion and written instructions on use were 'very satisfactory'. Very few individuals felt that any of these features were unsatisfactory. It was very gratifying to find that the patients had such positive views regarding these features as there is much debate in the literature regarding the most appropriate style of the PHR.

When the professionals were asked about a range of features of the PHR the results were not as encouraging as those of the patients'. It was disappointing to find that almost half of the professionals (47%) felt that the size of the PHR was 'unsatisfactory'. This was quite surprising as only 12% of the patients were of this opinion. The professionals, however, appeared to be more in favour of the colour-coded sections as 25% found these to be 'very satisfactory', while 59% felt that they were 'mostly satisfactory'. The font size used in the PHR also appeared to be acceptable, with only 11% of professionals judging it to be 'unsatisfactory'. Unfortunately over half (56%) of professionals stated that the ease of completion of the PHR was 'unsatisfactory'. This is quite worrying as the completion of the PHR is a very important aspect of its use, and professionals and patients should be able to do so effortlessly.

When asked for suggestions regarding how the format of the PHR could be improved it is interesting to note that 50% of suggestions stated that the PHR should be smaller. Two individuals felt that there was too much detail in the PHR, while two others felt that coloured identification tabs should be used in the PHR.

The section of the PHR, which provided the patients with useful information and phone numbers, was called 'Your Diary'. When the patients were asked how useful they found this section almost one third (30%) stated that it was 'very useful', while 46% felt that it was 'quite useful'. Two individuals stated that it helped them to remember the side effects of their treatment, while two others stated that they could express their feelings in it. Unfortunately 22% (n = 10) of patients stated that this section was 'of little use' while two per cent felt that it was not useful at all.

It has been stated in the published literature that one area of concern with the use of the PHR is that of confidentiality (Liaw, 1993, McGrievy, 2002). However, it was encouraging to find that no patient in the present study stated that they had any worries concerning the confidentiality of information written in the PHR. It is also worth noting that only one professional mentioned 'confidentiality issues' as a potential disadvantage of the PHR.

At the end of the questionnaire patients were given the opportunity to write down any comments they had regarding the use of the PHR. A wide range of comments was expressed here. It was quite disappointing to find that four patients stated that no member of staff ever asked for their PHR. This is reflective of the generally negative responses from the staff questionnaires. Chetwynd et al, 2001, acknowledge that when the health professional appears to be busy or distracted in using the PHR the patients cease offering it at consultations. They feel that to obtain the most from PHRs many health professionals would have to change the way they deliver care.

Two patients stated that the PHR was an unwanted reminder of their cancer. It must therefore be recognised that although many patients benefit from having a PHR other patients may not want this constant reminder of their illness. This may indicate a need for increased counselling or support for such patients.

When the professionals were asked what effect they felt the PHR had on patient care the responses were somewhat disappointing. It was found that only 18% of professionals felt that the PHR had a 'positive effect' on patient care, while over three quarters (77%) felt that it had 'no effect'. When asked to comment on this, four professionals stated that the standards of professional care had not changed since introduction of the PHR.

When the responses of the question regarding the effect the PHR had on patient care were cross-tabulated with the various professions it was found that 50% (n=4) of the doctors felt that the PHR had a 'positive effect' on patient care, compared to just 8% (n=2) of the nurses. Similarly 89% (n=23) of nurses felt that the PHR had 'no effect' on patient care compared to 38% (n=3) of doctors. This would indicate that doctors are more likely than nurses to perceive the value of the PHR. Perhaps it is the case that the benefits of having personal medical notes immediately available to them are more noticeable to doctors than nurses. It may also be the

case that as it is the doctor who normally explains the important aspects of cancer care to the patient, they may greatly appreciate the information, which the booklet provides.

It was somewhat discouraging to find that only 23% (n=7) of the professionals who participated in the study stated that there were any advantages in using the PHR. Two professionals recognised that it was useful to have access to the patients' medical information if necessary, while two others stated that the PHR aided inter-professional communication. One professional felt that the PHR empowered the patient to deal with their illness.

Equally discouraging was the fact that 81% (n=30) of professionals felt that there were disadvantages in using the PHR. A wide range of disadvantages was noted here. The most common was that the PHR was too time consuming, followed by it being too big. The PHR was also said to result in repetitive record keeping, while others thought that the patients felt obliged to accept the PHR. Three individuals felt that the patient forgetting/losing their PHR may create a problem.

Two professionals were of the opinion that reading poor prognostic information may increase patient anxiety. This is not surprising as Fisher and Britten (1993) found that when 21 doctors were questioned about patients having the choice of viewing their own records, all of them expressed negative views that patients may be frightened, upset or misinterpret information. In the present study only two of the professionals considered this to be the situation. Another professional was of a similar opinion to a few of the patients who felt that a disadvantage of the PHR was that it is a constant reminder of their illness. This point was also put forward in the literature regarding PHRs (Crook, 1998).

Almost three quarters of professionals stated that the PHR increased initial consultation time. The average time given for such an increase was 17.5 minutes. This would account for the time taken for the doctor to inform the patient of the potential benefits of the PHR, offer it to them and subsequently explain how to use it. The extra time required here has appeared in the literature as an argument against PHRs. In a study by Liaw (1993) it was found that 62% of GPs expressed concerns with the extra paperwork involved with PHRs. Contrary to the findings of Liaw (1993) only 35% of professionals in the present study stated that the PHR increased subsequent consultation time, and the average time given here was 6.6 minutes. These findings do not provide a sufficient argument against the use of the PHR.

Information was provided in the PHR explaining to the professionals how to use the PHR. It was encouraging to find that 70% of professionals felt that this information was 'quite helpful', while nine per cent felt that it was 'very helpful'. Over half (51%) of the staff who participated felt that healthcare professionals required additional education regarding the PHR. Four individuals stated that professionals required such education to encourage the use of the PHR. This is in agreement with Chetwynd et al (2001) who stated that education of professionals may extend and enhance the use of the PHR, while Cross (2002) feels that clinicians, in particular, need educating about the reasons to share data. One individual suggested that non-nurse professionals required extra education regarding the PHR. As few professionals other than doctors and nurses returned the questionnaires, it may be the case that therapists, radiographers and others are unaware of the existence/benefits of the PHR, and therefore such education may increase the use of the PHR.

When the professionals were asked if they felt the PHR was a valuable asset to patient care the results were surprising considering the previous answers they had given. It was found that over half of professionals felt that the PHR was a valuable asset to patient care. It may therefore have been the case that when starting to complete the questionnaire the professional may not have given the PHR much thought, however, through the completion of the questionnaire they may have been forced to think about it and realised that it is of more value to both themselves and patients than they had at first thought. It should be mentioned here that all six doctors believed that the PHR was a valuable asset to patient care, compared to only 50% (12) of nurses. This may again imply that doctors appreciate the value of the PHR more so than nurses.

A final question asked the professionals if they had any other suggestions as to how the process of using the PHR could be improved. Three professionals felt that better training should be provided. This could take the form of training days for the professionals. Such education may enlighten the professionals as to the benefits of using the PHR, thus encouraging its use. Two professionals felt that the PHRs should be distributed at more than one point. This may be beneficial in that some patients who refused the PHR when it was first offered may in fact like to receive one at a later stage in their cancer journey.

Hospitals see many patients every day and it is often difficult to remember which patients have PHRs and which do not. One professional suggested that when a patient accepts a PHR a

colour sticker should be put on their medical notes. Therefore when the professional is referring to the patient's notes during a consultation the sticker will remind them to ask the patient for their PHR.

It was reassuring to find that all six of the PHRs, which were reviewed using the 'Document Checklist', had been completed. It was not surprising that the Checklists revealed that the PHRs were only used by Doctors (including GPs), nurses, patients and family members.
The average length of time the PHR was used was 13.8 weeks. After this time the patient may have become accustomed to their medication regimen, treatment, and its' side-effects and so may not have relied on the PHR as they did at first. It may also have been the case that treatment had finished and they no longer felt the need for the PHR.

It was found that in five of the six PHRs assessed the recorded information was said to be clearly written. This was encouraging as it is often the case that the originator of information may understand what has been written, but difficulties can arise when other parties become involved (Borrachero et al, 2002). Research by Borrachero et al (2002) found that of the medical documents they assessed 15% were so illegible that the meaning was unclear. They go on to suggest that it is time to say goodbye to manuscript in medical notes. However, the results of this study do not point to such an extreme recommendation.

In all six of the PHRs assessed recorded information was found to be up-to-date and completed in the correct place, and in five the information was also accurate, comprehensive and easy to understand. Such findings would indicate that the professionals who use the PHRs appear to take time and care to complete them so that the information can be clearly understood by others. This is a very important aspect in the use of PHRs as the PHR would hold no value to patients or professionals if the content was indecipherable.

In five of the PHRs assessed all sections had been used. The section used most often was the 'Chemotherapy Section' while in one PHR the 'Medication Section' was used most often. It appeared that the PHR was most commonly used by staff to communicate with colleagues. While in four of the PHRs the professionals gave the patient a written explanation of their care. In half of the PHRs professionals had recorded dates of further investigations and treatments. Finally, it was reassuring to find that in all six PHRs assessed there was enough room for the required information to be written.

Limitations of the study

- It appeared that some professionals completing the questionnaires had not given the issue of PHRs much thought. As at the beginning of the questionnaire they came across as having quite negative views regarding the PHR, but at the end of the questionnaire their views were more positive.

- Patient interviews/focus groups as part of the research may have helped create a fuller picture of the use of PHRs in cancer care.

- Only six PHRs were assessed using the Document Checklist. The value of this section of the results may have been enhanced if a larger number of PHRs had been assessed in this way.

Conclusion

The aim of the PHR is to provide an informal record completed by professionals and carers at primary, secondary and tertiary level. The PHR will be owned by the patient and presented to hospital staff for completion at each attendance. This study aimed to evaluate the oncology PHR for patients in Northern Ireland.

The PHR in this study was designed after a number of years of research and careful consideration by an experienced steering group. Over a period of three months the PHR was offered to all new patients presenting with solid tumour cancers at their second attendance (after initial diagnosis), in either the Cancer Centre or their Cancer Unit. Questionnaires were then used to evaluate the overall effectiveness of the PHR. Two questionnaires were designed; one for patients and another for staff. A Document Checklist was also created to assess how the PHR had been completed.

Overall the results of the study would suggest that there are benefits of introducing an oncology PHR to Northern Ireland. The majority of patients felt that the PHR made making decisions about their treatment easier, made them feel better informed about their situation, helped them to understand their illness/treatment, and enabled/reminded them to ask questions about their condition. Almost two thirds (61%) of the patients felt that the phone numbers provided were 'very useful'.

When asked about a range of features of the PHR. e.g., size, colour coded sections, ease of completion, written instructions on use and size of print, it was established that the majority of patients were very satisfied with these aspects of the PHR.

Over three quarters (78%) felt that the 'Your Diary' section of the PHR was useful to some degree, while none of the patients stated that they had any worries regarding the confidentiality of information written in the PHR.

When the staff questionnaires were analysed it was found that most professionals believed the PHR was helpful concerning patient knowledge and the recording of patient details. Opinions

however were not so positive regarding issues such as, professional knowledge and compliance with medical instructions.

Professionals suggested that the use of the PHR aided inter-professional communication, was helpful if patients wanted to keep records of their own details, was useful in accessing patient information, and empowered the patient to deal with their illness. Some disadvantages were also put forward by the professionals. The most common of these was that the PHR was time-consuming and too big, while it was also suggested that the PHR involved repetitive record keeping and that patients felt obliged to fill it in. The professionals were generally quite satisfied with the colour-coded sections and font size in the PHR, however, several felt that the PHR should be smaller. Over half of the professionals were of the opinion that additional professional education regarding the PHR was necessary.

When a number of PHRs were assessed using the Document Checklist the results were very encouraging. In all PHRs assessed the recorded information was found to be clearly written, accurate, up-to-date, comprehensive, easy to understand and completed in the correct place. In all but one of the PHRs surveyed all sections had been used, while in all of the PHRs there appeared to have been enough room for the required information. It was found that in five of the assessed PHRs the professionals 'communicated with other professionals', while in four cases the professionals had used the PHRs to 'give a written explanation to the patient'.

It is recognised that the use of an oncology PHR may duplicate current patient notes, whilst adding to an already heavy workload for staff. However, there is no doubt that the PHR brings many advantages to cancer care, most importantly being the improved inter-professional and patient-professional communication, while also enhancing the patients' overall knowledge of their situation.

It can therefore be concluded that the introduction of an oncology PHR to Northern Ireland would appear to be an advantageous idea, much welcomed by patients and professionals alike.

Recommendations

1. During a consultation/hospital appointment professionals should ask the patient for their PHR. It is important that the patient does not perceive the professional to be disinterested in the PHR, or feel that the professional does not have enough time to complete the PHR. By doing this the patient would therefore be encouraged to use the record.

2. Although it is important that professionals complete the PHR, they must exercise caution so as not to cause any unnecessary worry to the patient or their loved ones. Therefore, they should not write anything in the PHR, which they would not discuss openly with the patient.

3. Additional education regarding the benefits of the PHR should be provided for professional staff. This training could be in the form of study days, workshops or seminars. Such education may highlight the benefits that PHRs bring to cancer care, so that professionals will be more likely to see the extra time and paperwork required as being worthwhile, and will therefore be more likely to use the PHR.

4. Healthcare professionals should be encouraged to use the PHR to communicate with other colleagues involved in the patient's care, as this is essential to obtain maximum benefit from the PHR.

5. Following on from the previous recommendation it is important that all members of the multidisciplinary team, not just doctors and nurses, involved in the patient's care use the PHR. Other professional colleagues include therapeutic radiographers, physiotherapists, occupational therapists, social workers, chaplains, dietitions, speech and language therapists and pharmacists.

6. The PHR should be offered to patients at their first doctor/hospital appointment after initial diagnosis. However, if they do not accept the PHR at this stage they should be made aware of its availability while in hospital.

7. The research found that patients over the age of 60 years were less likely to 'always' carry the PHR and more likely to 'never' carry the PHR than those under 60 years. Therefore patients aged over 60 years should receive some additional form of encouragement to use the PHR, thus taking a more active role in their health care.

8. When a patient accepts a PHR a coloured sticker should be put on their Medical Notes (Hospital and G.P.). Consequently, when the professional refers to the patient's notes at a consultation/hospital visit, they will be reminded to ask the patient for their PHR.

9. The value of the PHR to the patient should be communicated to the multidisciplinary team with the aim of encouraging them to complete the patient's PHR.

References

Alcock, C (2000) The Teamwork File – A feasibility study. NCA Newsletter, 8-9.

Alcock, C. Drury, M. Fitzpatrick, R. Harcourt, J. Jones, L. Minton, M., & Yudkin, P. (2000) Patients with cancer holding their own records: A randomised controlled trial. British Journal of General Practice, 50, 105-110.

Bailey, F. Chey, T. Jeffs, D. Nossar, V., & Smith, W. (1994) Retention and use of personal health records: A population based study. Journal of Paediatric Child Health, 30 (3), 248-252.

Balazs, J. R., & Reuler, J. B. (1991) Portable medical record for the homeless mentally ill. British Medical Journal, 303, 446.

Baldry, M. Cheal, C. Fisher, B. Gillet, M., & Huet, V. (1986) Giving patients their own records in General Practice: Experience of patients and staff. British Medical Journal, 292, 596-598.

Britten, N., & Fisher, B. (1993) Patient access to records: Expectations of hospital doctors and experiences of cancer patients. British Journal of General Practice, 43, 52-56.

Burnard, P (1996) Teaching the analysis of textual data: An experimental approach. Nurse Education Today (16), 278-281.

Chetwynd, N. Cheung, W. Y. Cohen, D. R. El-Sharkawi, S. Finlay, I. Lervy, B. Lango, M. Malinovszky, K., & Williams, J. G. (2001) Pragmatic randomised trial to evaluate the use of patient held records for the continuing care of patients with cancer. Quality In Healthcare, 10, 159-165.

Cornbleet, M. (1998) The National Patient Held Records Programme. Scottish Partnership Agency for Palliative and Cancer Care and National Council for Hospice and Specialist Care Services. Patient Held records in Palliative and Cancer Care – Report of a Conference.

Crack, L. (1998) The User's Point Of View. Scottish Partnership Agency for Palliative and Cancer Care and National Council for Hospice and Specialist Care Services. Patient Held records in Palliative and Cancer Care – Report of a Conference.

Cross, M. (2002) Owned by the patient. Government Computing, 19.

Drury, M. Harcourt, J., & Minton, M. (1996) The acceptability of patients with cancer holding their own shared-care record. Psycho-Oncology, 5, 119-125.

Fierman, A. H. Legano, L. A., & Rosen, C. M. (1996) Immunisation status as determined by patient's hand-held card versus the medical card. Archives in Paediatric Adolescent Medicine, 150 (8), 863-866.

Finlay, I. G., & Wyatt, P. (1999) randomised cross-over study of patient-held records in oncology and palliative care. The Lancet, 353, 558-559.

Forbes, K. Foster, S., & Webster, J. (1996) Sharing antenatal care: Client satisfaction and use of the 'patient-held record'. Australia and New Zealand Journal of Obstetrics and Gynaecology, 36 (1), 11-14.

Giglio, R. J., & Papazian, B. (1986) Acceptance and use of patient-carried health records. Medical Care, 24 (12), 1084-1092)

Gilhooly, M. L. M., & McGhee, S. M. (1991) Medical Records: Practicalities and principles of patient possession. Journal of Medical Ethics, 17, 138-143.

Hannigan, A., & Stafford, A. (1997) Client held records in community mental health. Nursing Times, 93, 7.

Hayward, K. (1998) Patient-held oncology records. Nursing Standard, 12 (35), 44-46.

Higginson, I. McCarthy, M., & Wade, A. (1990) Palliative Care: Views of patients and their families. British Medical Journal, 301, 277-281.

Hooker, L., & Williams, J. (1996) Patient-held shared care records – bridging the communication gaps. British Journal of Nursing, 5 (12), 738-741.

Jones, B. (1990) Dear Diary. Nursing Times, 86 (22), 31-34.

Liaw, S. (1993) Patient and General Practitioner perceptions of patient-held health records. Family Practice, 10, 406-415.
Macmillan Cancer Relief (1999) The Cancer Guide – Information for people with cancer and those who care.

MacFarlane, A., & Saffin, K. (1990) Do General Practitioners and Health Visitors like 'parent-held' child health records? British Journal of General Practice, 40 (332), 106-108.

McGrievy, P. C. (1995) Using client-held records in community nursing practice. Mental Health Nursing, 15 (3), 26-27.

Stevens, M. M. (1992) "Shuttle Sheet": A patient-held medical record for paediatric oncology families. Medical Paediatric Oncology, 20 (4), 330-335.

Scottish PHRIEND, www.ncl.ac.uk/chsr/research/hta/lb/phriend/htm.

Appendicies

Appendix 1 Cancer Units

Altnagelvin Area Hospital
Glenshane Road
Londonderry
BT47 6SB

Antrim Area Hospital
Bush House
45 Bush Road
Antrim
BT41 2QB

Belfast City Hospital
Lisburn Road
Belfast
BT9 7AB

Belvoir Park Hospital
Hospital Road
Belfast
BT8 8JR

Craigavon Area Hospital
68 Lurgan Road
Portadown
BT63 5QQ

The Ulster Hospital
Upper Newtownards Road
Dundonald
BT16 1RH

Appendix 2

Staff Questionnaire

Patient Held Record (PHR)

Please fill in your answers or tick the appropriate box.

Please return the questionnaire, completed or not completed, in the stamp addressed envelope provided by

Tuesday 10th September 2002

1. **Profession** _____

2. **Gender** Male ☐ Female ☐

3. **Please state the number of years since your initial registration or qualification** _____years

4. **What effect do you think the patient held record had on patient care?**

   Positive effect ☐ No effect ☐ Negative effect ☐

   Please comment _____

5. **How beneficial do you feel the PHR was regarding the following issues?**

	Extremely helpful	**Somewhat helpful**	**Not very helpful**	**Not helpful at all**
Patient knowledge	☐	☐	☐	☐
Professional knowledge	☐	☐	☐	☐
Recording of patient details	☐	☐	☐	☐

Patient-professional communication	☐	☐	☐	☐
Interprofessional communication	☐	☐	☐	☐
Compliance with medical instructions	☐	☐	☐	☐
Encouraging patient self-reliance	☐	☐	☐	☐

6. **Are there any other advantages of using the PHR?**

   Yes ☐ No ☐

   Please comment _____

   _____

   _____

7. **Are there any disadvantages of using the PHR?**

   Yes ☐ No ☐

   Please comment _____

   _____

   _____

8. **Did the use of the PHR alter the initial (i.e. when the PHR was issued) consultation time?**

   Yes ☐ No ☐

   If yes, by approximately how many minutes? _____

9. **Did the use of the PHR alter subsequent consultation times?**

   Yes ☐ No ☐

   If yes, by approximately how many minutes? _____

10. **What did you think of the 'Information for professionals' on pages 5 & 6 of the PHR?**

    Very Helpful ☐ Quite Helpful ☐ Not very helpful ☐ Not helpful at all ☐

    Please comment _____

    _____

11. **Do you feel professionals require additional education on using the PHR?**

    Yes ☐ No ☐

    Please comment _____

    _____

    _____

12. Please indicate your satisfaction with each of the following features of the PHR.

	Very Satisfactory	Mostly Satisfactory	Unsatisfactory
Size of the PHR	☐	☐	☐
Colour coded sections	☐	☐	☐
Font size	☐	☐	☐
Ease of completion	☐	☐	☐

13. If you have any ideas on how the design could be improved, please comment.

_____

_____

_____

_____

14. Overall, do you feel the PHR is a valuable asset to patient care?

Yes ☐ **No** ☐

Please comment _____

_____

_____

15. **If you have any suggestions as to how the process of using the PHR could be improved, please comment.**

_____

_____

_____

_____

_____

Thank you for completing the questionnaire. We very much appreciate your contribution to this work.

Please return the questionnaire in the stamp addressed envelope provided.

Appendix 3

Patient Questionnaire
Patient Held Record (PHR)

Please fill in your answers or tick the appropriate box. Some questions ask for additional comments which you may give if you so wish. Please return the questionnaire in the stamp addressed envelope by Tuesday 10th September 2002

1. **How old are you?** _____ years
2. **Are you** Male? ☐ Female? ☐
3. **What is your understanding of your diagnosis?** _____

_____

4. **In which area do you live?**

Belfast	☐	Co. Antrim (other than Belfast)	☐		
Co. Armagh	☐	Co. L.Derry	☐		
Co.Down	☐	Co. Fermanagh	☐	Co. Tyrone	☐

5. **Which hospital issued you with the PHR?**

Antrim Area Hospital	☐	Belvoir Park Hospital	☐
Altnagelvin Hospital	☐	Craigavon Hospital	☐
Belfast City Hospital	☐	The Ulster Hospital	☐

6. **Was the PHR given to you at the most useful time?**

Yes ☐ No ☐

7. If no, what would have been a better time for the PHR to have been given to you?

_____

8. Who gave you the PHR?

Doctor ☐ Nurse ☐

Radiographer ☐ Other, please state profession below

_____

9. How often do you carry the PHR with you?

I always have my PHR with me ☐

I usually have my PHR with me ☐

I only take my PHR with me when I'm going to radiotherapy/chemotherapy appointments ☐

Never ☐

10. On what other occasions has the information in your PHR been used?

Other hospitals ☐

Out of hours GP ☐

District nurse ☐

Other ☐

Please give details _____

_____

Own GP ☐

11. If you are willing for your GP to be contacted on the usefulness of the PHR please state their name and address below.

Name: _____

Address: _____

_____

12. Please say whether you agree or disagree with each of the following statements.

The PHR:

	Agree	Disagree
Makes decisions about my treatment easier	☐	☐
Makes me feel better informed about my situation	☐	☐
Helps me understand my illness/treatment	☐	☐
Makes me feel more in control of my situation	☐	☐
Reminds me to take my medication	☐	☐
Enables/reminds me to ask questions about my condition	☐	☐
Helps me to explain my illness to family and friends	☐	☐

13. The phone numbers provided in the PHR were:

Very useful ☐ Quite useful ☐ Of little use ☐ Not useful at all ☐

14. **Please indicate your satisfaction with each of the following features of the PHR.**

	Very Satisfactory	Mostly Satisfactory	Unsatisfactory
Size of the PHR	☐	☐	☐
Colour coded sections	☐	☐	☐
Size of print used	☐	☐	☐
Ease of completion	☐	☐	☐
Written instructions on use	☐	☐	☐

Any additional comments _____

15. **How useful did you find the "Your Diary" section of the PHR?**

Very Useful ☐ Quite Useful ☐ Of little use ☐ Not useful at all ☐

Please comment _____

16. **Did you have any worries concerning the confidentiality of the information written in your PHR?**

Yes ☐ No ☐

Please comment _____

_____

17. **If you have any suggestions as to how the PHR could be improved, please comment.**

_____

_____

_____

18. If you have any other comments about the PHR, please include them below.

_____

_____

_____

We may wish to interview some patients at a later stage. If you would be happy to be contacted by the researcher please provide your contact details in the section below.

If you do not wish to be approached do not fill in the details below.

This will in no way affect the care you receive as a patient.

Name: _____

Address: _____

_____

Phone number: _____

Thank you for completing the questionnaire.

We very much appreciate your contribution to this work.

Please return this questionnaire to us in the stamp addressed envelope provided

Appendix 4

Document Checklist
Patient Held Record (PHR)

BPH No.	
Unit No.	

1. **Date of patient's first hospital visit (this illness):** _____ / _____ / _____

2. **Date PHR issued:** _____ / _____ / _____

3. **Date PHR checked:** _____ / _____ / _____

4. **Was the PHR used?** Yes ☐ No ☐

5. **Who was the PHR used by?**

Doctor	☐	Nurse	☐
Occupational Therapist	☐	Dietition	☐
Physiotherapist	☐	Pharmacist	☐
Speech & Language Therapist	☐	Social Worker	☐
Radiographer	☐	Patient	☐
Family member	☐	Other_____	

6. **How long has the PHR been used for?** _____weeks

7. **Was the recorded information:**

	Yes	**No**	**Sometimes**
Clearly written?	☐	☐	☐
Accurate?	☐	☐	☐
Up-to-date?	☐	☐	☐
Comprehensive?	☐	☐	☐
Easy to understand?	☐	☐	☐
Completed in correct place?	☐	☐	☐

8. Were all sections used?

Yes ☐

No ☐ Section used most often _____

Section used least often _____

9. Did all professionals use the PHR?

Yes ☐

No ☐ Used most often by _____

Used least often by _____

10. Did professionals use the PHR to:

communicate with other professionals ☐

give written explanation to the patient ☐

make appointments ☐

record dates of further investigation/treatment ☐

Other _____

_____

11. Was there enough room on the PHR for the information required?

Yes ☐ No ☐

Appendix 5 Membership of the Working Group

- Miss A. I. Duddy, Director of Nursing, Altnagelvin Area Hospital **(Chair)**
- Mrs H. Baird, Executive Director of Nursing & Quality, Homefirst Community Trust
- Dr D. Davison, Macmillan Clinical Fellow in Community Cancer, Dunluce Health Centre, Belfast
- Mr D. Johnson, Senior Nurse Advisor/Commissioning Nurse, NHSSB
- Mrs E. Henderson, Oncology Nurse Manager, Belvoir Park Hospital, Belfast
- Mr R. Henry, Ward Manager, Belvoir Park Hospital, Belfast
- Mrs R. Smith, Clinical Services Manager, Ulster Hospital, Dundonald
- Mr P. O'Halloran, Senior Nurse Practice Development, Belfast City Hospital
- Dr G. Johnston, Macmillan Non-Clinical Lecturer, Dunluce Health Centre, Belfast
- Mrs A. McParland, Nursing Special Projects Officer, United Hospitals Trust
- Dr K. Dunne, Nurse Tutor, North and West In-Service Education Consortium
- Dr P. Hannigan, AHPs Advisor, NHSSB
- Mrs D. McDowell, Social Worker, Craigavon Area Hospital
- Miss J. Rankin, Superintendent Physiotherapist, Belvoir Park Hospital
- Dr G. Daly, Lead Cancer Clinician, Altnagelvin Area Hospital
- Dr M. Palmer, G.P., Lisburn Health Centre
- Mrs Margaret Irwin NHSSB patient (now deceased)
- Mrs M. O'Kane, Ulster Cancer Foundation, Belfast

Appendix 6 Regional Patient Held Record Group

Dr Dermot Davison, Dunluce Health Centre, Belfast

Professor George Kernohan, University of Ulster, Jordanstown

Ms Hazel Baird, Homefirst Community Trust

Mrs Liz Henderson, Belfast City Hospital

Ms Ruth Smith, The Ulster Hospital, Dundonald

Mr Raymond McMillen, Campbell Commissioning Group **(Chair)**

Dr Gail Johnston, Dunluce Health Centre

Dr Kate Sullivan, University of Ulster, Jordanstown

Mr David Johnston, NHSSB

Miss Jane Rankin, Belvoir Park Hospital

Ms Irene Duddy, Altnagelvin Area Hospital

Mr Michael Taylor, Campbell Commissioning Group

Mr Ian Clarkson, NHSSB

Ms Liz England, Altnagelvin Area Hospital